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California Department of Aging Presents
A Primer on Aging Programs Common Dataset
April 2006

PURPOSE OF THIS PRIMER

The purpose of this document is to introduce and explain the concept of the California Department of Aging's (CDA) proposed **Common Dataset** to Area Agencies on Aging (AAA), their network of service providers, and the public at large.

This document explains the rationale supporting the development of the proposed Common Dataset and the need for software technology improvements. It also answers some common questions and concerns raised in regard to a Common Dataset. Finally, at the end of this document, you may select the button that says "**I HAVE COMMENTS**." This will permit you to provide your comments on the proposed Common Dataset back to CDA. Public comments and questions, along with our responses, will be grouped and posted on our web site. Your feedback is important and welcome.

DEFINITION OF COMMON DATASET

What is a "Common" Dataset?

A common dataset is a set of instructions and data specifications that standardize data elements and data definitions across multiple programs. For example, Activities of Daily Living (ADL) data elements and definitions would be standardized across multiple programs and services. ADLs and definitions in one program would match ADLs and definitions in another. As it is now, these data definitions and coding can be, or are, slightly different and therefore can not be combined for analysis.

The primary rationale for the proposed aging network Common Dataset is to establish a common set of data across all Older Americans Act (OAA) and Older Californians Act (OCA) programs for the purpose of creating a statewide management information system (MIS). Such a system would make it possible, both at the local and state levels, to: (1) better analyze the characteristics and needs of program clients, (2) identify programs that frequently share the same clients, and (3) to track changes in program client demographics over time. This information would be instrumental for short and long term policy development, program planning, and resource management.

A Common Dataset does not necessarily prescribe reporting requirements. Rather, it spells out the data elements and definitions that, **IF** required for reporting, must be used.   This differs from a "minimum dataset", which identifies the minimum data that must be collected and reported.

BACKGROUND

Over the past twenty years, there have been various California projects and proposals calling for some form of common data across aging services programs.   As far back as 1986, the SEED project, under the general guidance of the Andrus Gerontology Center at the University of Southern California, proposed to integrate long-term care management data across several programs to facilitate a system of community-based long-term care.   Discussion about tracking client and utilization data across funding streams and programs is not new.

The impetus for this latest effort came with the passage of **SB 910** (Vasconcellos, Statutes of 1999, Chapter 948). This statute requested the University of California to develop a comprehensive long term master plan for California's aging population, including a "longitudinal database" of older Californians.

In March 2003, the University of California (UC) issued a *"Special Report - Planning for a Comprehensive Database on Aging Californians: Meeting Public Policy and Research Needs for Better Information,"* 2003, Frank Neuhauser, Henry Brady, and Jason Seligman. This report lays out a strategy for improving the data available for policy making and concluded that to develop good comprehensive statewide data on California's aging population it is more cost efficient and constructive to build on the existing data system, and supplement it when necessary, rather than develop an entirely new longitudinal database.

Benefits would be derived from combining certain information from Census on the whole aging population to the population that is eligible, in need, and have actually been served by OAA/OCA services. This will result in improved identification of client needs, service utilization, and potential unmet needs.

However, the authors expressed serious concerns about the existing aging network data system's ability to provide both accurate data and data that could be linked with other databases. The UC report recommended:

> *"Some aspects of the data-gathering effort should be standardized. …We suggest a minimum dataset to provide the necessary data in a way that enables linkage with other data sources."* (Page 11) [1]

"The first and most important step in creating a Comprehensive Database on Aging Californians is to focus on improving the data collected by local Area Agencies on Aging and their providers." (Page 28)

This is a part of an overall strategy of using data on an evolving aging population, tracking the demographic changes in the population over time, and using OAA/OCA data as an important part of local and State planning, resource allocation, and policy decision making. With these data, local service providers, AAAs, and the State could analyze the service utilization of those clients who use more than one program or service. Systematically identifying how many clients are using multiple programs and services would help at the micro level to do better client service coordination. At the macro level, it would help in targeting program coordination efforts and the potential benefit of co-locating certain services.

PARAMETERS USED IN DEVELOPING THE OAA/OCA COMMON DATASET

The parameters used in developing this Common Dataset include:

- All Older Americans Act and Older Californians Act Programs and Services should eventually be included in the Common Dataset.[2] The common dataset will meet the challenges of preparing for a comprehensive and longitudinal database for aging Californians [SB 910; **Welfare and Institutions Code, Section 9101.5**].

- For the OAA programs, we are required to use the National Aging Programs Information System. The common dataset will meet both the requirements of federal National Aging Program Information System (NAPIS) and the requirements of a statewide integrated data system for California's OAA and OCA programs. NAPIS is a requirement of the federal Administration on Aging, which has oversight authority for the implementation of the OAA. Any statewide standards above and beyond NAPIS would be governed by CDA state standards.

- Client-Specific Data Are Needed. Client-specific data are needed for quality control (including controls for unduplicated client counts/registered clients), management analysis, public policy research, and resource distribution decisions.[3] Aggregate data cannot be used for this purpose as it cannot connect utilization patterns to client characteristics, whereas client-specific data can.

- Additional "Registered Services" Are Needed. All OAA and OCA services may be considered for "registered" status, unless specifically exempt.[4]

Proposed exempt services at this point are Information and Assistance services and Outreach services. Registered services require client-specific data be collected at the local level, be uniquely identified to prevent duplication of the total count, and identify specific individuals with their specific utilization and profile data. Therefore, the data collected would be "client-specific" data connected to each individual person served.[5] For example, the system would be able to identify how many OAA/OCA services each individual had used within a year.

- Sources Used in Establishing Our Standards. The basic sources of standards drawn from are: (1) NAPIS; (2) the decennial U.S. Census; (3) California Health Interview Survey (CHIS); and (4) National Health Interview Survey (NHIS). These four sources of standards allow for alignment of the common dataset with other larger data systems.

- Missing Data Accountability. Missing data from each applicable data variable must be accounted for in the local AAA system. The UC Special Report (p. 10) suggests that complete data are vital for anti-bias purposes. However, the OAA requires services to be rendered, even in the absence of data, so missing data needs to be reduced to the greatest extent possible, but also identified when the data truly is missing.

[1] The report refers to a "minimum" dataset rather than a "common" dataset, but for our purposes here the principles are the same. A minimum dataset is reportable data.
[2] For a complete list of these programs and services go to , then select Programs and Services in the left hand menu.

UNIQUE IDENTIFIERS AND PRIVACY CONSIDERATIONS

The most sensitive issues in client specific level databases pertain to protecting the use and disclosure of personal information and personal identification.

[3] See UC Special Report, Executive Summary, page vii.
[4] Currently unregistered services in NAPIS include: Legal services, Transportation, Information and Assistance, Outreach, and Nutrition Education, as well as Other services.
[5] CDA has piloted efforts over the past several years that demonstrate that more registered services can be achieved.

This new proposal does **not** envision collecting, storing, and analyzing private information on individuals at the State level. It is not proposed that this new state level database will store individual names, addresses, or sensitive health information. However, in order to be able to cross tabulate data across services, some form of unique identification number must be attached to individuals in order to allow client profile information to be connected to utilization data and to

control for duplication. In this proposal we are suggesting a combination of unique identifying numbers be used to control for this. This could include:

> A Unique Identifier Number
> The Client's Home Phone Number
> The Client's ZIP Code
> The Client's Date of Birth (DoB)
> Planning and Service Area (PSA) Number [1 to 33]

A Word About the Social Security Number (SSN)

While the software system being designed to incorporate this new Common Dataset will include a capacity or capability to use the SSN (or portion thereof), if and when necessary, this proposal is not suggesting the use of a mandatory SSN as the unique identifier number for clients.

OTHER CONSIDERATIONS

Several other considerations must be kept in mind as we implement a Common Dataset for OAA and OCA programs. First and foremost, we must adapt to federal changes in NAPIS. Second, CDA will need to modernize its information technology to allow greater flexibility for warehousing data and using web-based communications. And third, CDA must set a strong foundation for the envisioned future system and its expansion. We will start by making all necessary NAPIS changes and include Title III E, Family Caregiver Support Program, in the electronic reporting. Over the next few years, we will gradually include all other OAA and OCA programs.

Implementing Federal NAPIS Changes

This effort involves catching up with the federal AoA NAPIS changes that were issued in November of 2004 and shifting from an aggregate reporting system to a client specific system.

Upgrading the CDA Technology to Handle a Client-Specific Database

The envisioned new database will be a component in CDA's new client level MIS that in the future will be referred to as the **California Aging Reporting System** (**CARS**). Electronically incorporating all OAA and OCA program data in the data reporting process, establishing a common dataset for these programs, and beginning to collect client level data are the first fundamental steps. This involves migrating to a web-based software system that will facilitate an easier data reporting process.

Common Dataset and CARS Implementation

Area Agencies on Aging (AAAs) and their service providers will eventually be asked to adopt this proposed "common" set of data as a part of the steps described in SB 910 for developing a longitudinal database. CARS implementation will come first followed by certain programs being phased into the system over several years. In 2006, CDA will begin this process by incorporating the NAPIS SPR and Title III E (Family Caregiver Support Program) data. We project CARS to be in place and fully tested for the start up of State Fiscal Year 2007-08. Other programs will be phased in and integrated over time.

Activity	Estimated Time to Complete
Configuration of State System	June 06 – August 06
Specifications Available to AAAs	July 2006
Testing – Initial Pilot and Phase in AAAs	October 06 – June 07
Cutover to CARS - AAAs Required to Begin Submitting Data over New Reporting System	July 1, 2007

Again, not all of the elements in the common dataset will be reported to CDA, but the dataset requirements ensure a system is in place that is capable of collecting and extracting such information if and when needed. Some data may, in fact, be better suited for collection on a sample basis rather than from the routine MIS (see pages 13 and 14 of the UC Special Report).

QUESTIONS AND ANSWERS

How will this change my services or how will it affect my data collection and reporting?

The first changes will only be to upgrade to the minimum AoA OAA NAPIS requirements. This affects NAPIS reporting and Title III E Family Caregiver Support Program only.   The intent is to first come into compliance with existing federal reporting rules (see AoA NAPIS Instructions of Nov. 1994).

Over a period of several years, all other programs and services within the Common Dataset will gradually have to adopt changes to data and data definitions so that all programs and services meet OAA and OCA standards.

Area Agencies on Aging and OAA/OCA service providers must begin planning for the necessary adjustments to bring their databases into alignment with the Common Dataset.

Will I have to report all these data?

Not necessarily. Although the Common Dataset lays the foundation for consistent data reporting across all programs, it does not replace "program reporting requirements."   Reporting instructions and specifications will be issued separately for each OAA/OCA program or service, and some programs may be exempt from collecting and reporting certain data. Individual program data will be reviewed after implementation and individual program reporting requirements may be modified to conform to the Common Dataset. This will allow data to be tabulated across OAA/OCA programs.

I can't ask people to provide social security numbers!

We do not envision the SSN to be a mandatory unique client identifier. However, the CARS software system will have a capacity or capability to collect SSN data should that be necessary in any particular circumstance.

Where does HIPAA come in?

HIPAA does not affect this part of the CARS planning or the Common Dataset. [See Program Memo 03-24 (P) available on our web site at http://www.aging.ca.gov/PM/PM_index.html].   HIPAA is only involved when transacting insurance. AoA and CDA have determined that OAA and much of the OCA data is not affected by HIPAA requirements.   There are some exceptions which will be covered in a separate document.

How does the Common Dataset relate to CARS?

The Common Dataset is one component of the CARS project. The CARS project is to install the needed technology to handle client specific data on a statewide database.

 RESOURCES

For a copy of the complete **UC Special Report**, go to our web site on http://www.aging.ca.gov/html/stats/demographics.html, then select the link "Planning for a Comprehensive Database" from the right-hand menu.

For a copy of the AoA **NAPIS** requirements document, click on http://www.aging.ca.gov/html/stats/demographics.html, then select "Federal Reporting Requirements - NAPIS Instructions November 2004" link.

For a connection to **Welfare and Institutions Code, Section 9101.5** (established by SB 910), click on http://www.aging.ca.gov/html/regs/lawsandregs.html, then select the "Welfare and Institutions Code" link.   Search for Section **9100 to 9114** under "General Provisions."

I HAVE COMMENTS
[Click here to submit your comments]

Comments may be submitted in writing through U.S. mail to the following address:

California Department of Aging
Attention: Susan Keim – Data Team
1300 National Drive, Suite 200
Sacramento, CA 95834-1992

Responses to U.S. Mail comments will be posted on website.